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| <b>13. ABSTRACT (Maximum 200 Words)</b><br>A large body of literature indicates that psychosocial support interventions for cancer patients, which provide specific cognitive-behavioral and coping skills training, are effective in the reduction of cancer pain, nausea, depression, and anxiety, and may improve indices of survival. However, few patients take advantage of available support groups, and these support groups do not typically provide the structured components demonstrated to result in positive outcomes. In our interactions with newly-diagnosed breast cancer patients, patients also cite logistical constraints (e.g., travel distance or lack of information) as reasons for non participation. Through the implementation of the currently-funded protocol, SURVIVE, substantial progress has been made in making structured supportive/informational group services more readily available to breast cancer patients. Although the computer-facilitated Internet-based group intervention was not significantly predicted changes over time in quality of life. These findings suggest that future efforts will need to clarify the role of computer versus professional facilitation and mechanisms by which participation can be maximized. |                                                                 |                                                                |                                                                                      |                                                |
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## Introduction

The following annual report elaborates progress made towards implementation of an Internet-based psychosocial intervention, *SURVIVE*, designed to provide information, support, and patient resources to breast cancer patients. The foundations of this intervention were completed as part of the trainee's master's thesis. These foundations include the development of a PERL 5.0 program that manages confidential communications between patients and the trainee's host computer over the Internet, the creation of a patient resource database specific to central Alabama, development of 6 structured intervention modules, and the establishment of a patient referral network.

A large body of literature indicates that psychosocial support interventions for cancer patients, which provide specific cognitive-behavioral and coping-skills training, are effective in the reduction of cancer pain<sup>1-5</sup>, nausea<sup>6-10</sup>, depression<sup>11-15</sup>, and anxiety<sup>16-20</sup>, and may improve indices of survival<sup>21-25</sup>. However, few patients take advantage of available support groups<sup>26-27</sup>, and these support groups do not typically provide the structured components demonstrated to result in positive outcomes.<sup>27-30</sup> In our interactions with newly-diagnosed breast cancer patients, patients also cite logistical constraints (e.g., travel distance or lack of information) as reasons for non-participation. Through the implementation of the currently-funded protocol, *SURVIVE*, substantial progress has been made in making structured supportive/ informational group services more readily available to breast cancer patients. Documentation of this progress is contained herein.

Psychosocial interventions have been shown to be efficacious in reducing depression, anxiety, pain, and nausea and in improving overall quality of life for cancer patients. However, the public health impact of traditional face-to-face psychosocial interventions for cancer is limited by factors such as geographic availability and low rates of participation. Studies confirm that supportive care programs are in high demand among cancer patients, yet only a small minority of patients are able to access existing services due to required travel time or symptoms associated with cancer treatment or progression of disease. Internet-based psychosocial interventions may be able to increase the public health impact of supportive care services by improving availability and reducing barriers to obtaining these services. The overall goal of this study was to implement and evaluate the effectiveness of an Internet-based intervention (SURVIVE) to increase the availability of structured psychosocial interventions to patients. To meet this goal, we developed and pilot-tested the SURVIVE intervention among a group of breast cancer patients. On the basis of this pilot-testing, a systematic recruitment effort was implemented, and all relevant endpoints were tracked using a database.

In this third and final year of funding, data reduction, analysis, and manuscript preparation goals have been met. Fifty-nine women with breast cancer agreed to participate in the study, completed the baseline assessment, and were randomized into either the waiting list control group ( $n = 30$ ) or the Internet-based APT ( $n = 29$ ). Three participants originally assigned to the waiting-list control condition and four participants randomized to the treatment condition failed to complete the second assessment. Eighteen participants assigned to the control group crossed-over into a treatment group after completing both a baseline and 12-week assessment. A more detailed description of the recruitment mechanisms and retention of participants is provided in Appendix A and B. The specific work-related objectives and current accomplishments are detailed below. Tasks 5 and 6 from our original *Statement of Work* described our research aims for the second year of funding.

#### *Task 5. Data Reduction and Analysis, Months 25-28.*

- a. Outcome data on health-related quality of life, depression/anxiety, patient satisfaction, coping, self-efficacy for coping, and positive contributions will be analyzed using SAS ver 8.0.
- b. A  $2 \times 3$  repeated measures analysis of variance will be performed for each primary dependent variable (HRQOL, satisfaction, anxiety, and depression) using a between-groups factor (control vs. intervention) and a within-groups factor (pre-test, 6-weeks, & 6-months).
- c. Follow-up analyses of significant main or interaction effects will be conducted, using hierarchical regression to evaluate potential mediating factors such as coping, self-efficacy for coping, positive contributions, and frequency of program participation.
- d. Structural equation modeling will be conducted using LISREL. Primary dependent variables without significant main or interaction effects in task 5b will not be included in the structural equation model. This analysis will only be performed if enough participants are enrolled ( $n > 120$ ) over the course of the study.

#### *Progress Made in Accomplishing Task 5*

With regard to task 5a, all questionnaire-derived data were collapsed into a single database using Microsoft Access. Additionally, for each participant Practical Extraction and Report Language (PERL) was used to characterize patterns of website usage and to extract text from messages posted to the online discussion group by participants over the course of participation in the trial. This text was then subjected to Linguistic Inquiry and Word Count (LIWC) analysis and all resulting variables were further collapsed into the formerly mentioned database. All subsequent data analyses were conducted with SAS v.8.0.

Because few participants completed time 3 questionnaires, all dependent variables were analyzed for between-group differences on time 2 variable scores after covarying for baseline variable scores. Using SAS version 8.00, general linear modeling was employed for all multivariate analyses of continuous dependent variables except where otherwise noted. Time two scores on outcome variables were analyzed only after adjusting for baseline values. To examine the effect of group size and initial randomization condition on subsequent participation in the groups, data obtained from cross-over control participants were included in the sample. Differences between the control and treatment conditions on non-continuous variables were tested using chi-square frequency analyses.

Baseline and follow-up scores on measures of quality of life and specific domains of quality of life are provided in Table 1. After adjusting for baseline scores, there were no significant follow-up differences between the waiting-list control group and the intervention group across any of the primary outcome measures. The treatment group did exhibit a trend towards higher scores on the FACT-G emotional well-being subscale,  $F(1,49) = 3.45, p = 0.07$ . Because use of the web site varied substantially among the participants assigned to the treatment group, the number of time participants accessed the coping exercises on the web site and total time spent using the web site were included as additional covariates. Again, there were no significant group differences for overall quality of life, perceived health status, number of reported physical symptoms, physical well-being, functional well-being, or social well-being. However, the treatment group exhibited significantly higher follow-up scores for emotional well-being than did the control group,  $F(1, 47) = 4.22, p = 0.047$ . Among all participants who were provided with access to the treatment condition, including those initially randomized into the treatment group and those who crossed-over into a treatment group at the time 2 assessment, participation was associated with improvements over time. After adjusting for the assessment immediately prior to beginning a treatment group, total time spent interacting with the web site was associated with reduced total IOES scores,  $F(1,35) = 4.92, p = 0.033$  and IOES avoidance,  $F(1,35) = 4.59, p = 0.039$ . Time of interaction with the treatment group was also associated with trends for reduced IOES hyperarousal,  $F(1,35) = 3.57, p = 0.067$ , reduced HADS depression scores,  $F(1,36) = 3.38, p = 0.074$ , reduced HADS anxiety scores,  $F(1,36) = 3.42, p = 0.072$ , greater use of approach-coping,  $F(1,38) = 4.01, p = 0.052$ , and greater emotional support,  $F(1,38) = 4.05, p = 0.051$ .

With regard to task 5c, we explored potential mediating factors (associated with baseline participant characteristics and actual participation in the online support group) that predicted changes across primary dependent variables. With regard to task 5d, structural equation modeling could not be performed due to an inadequate final sample size. However, the results of all mediational analyses are provided below.

#### ***Baseline Characteristics Associated with Outcomes.***

***Quality of Life Outcomes.*** Change in participants' perceived health status by the end of the 12-week study was significantly predicted by time since diagnosis,  $F(1,25)=4.09, p=0.05$ . Shorter intervals between diagnosis and participation in the study were associated with greater improvements in health status. Improved overall quality of life scores were associated with shorter time since diagnosis,  $F(1,19)=8.19, p=0.01$ , and greater annual household income,  $F(1,19)=4.23, p=0.05$ . After adjusting for these baseline characteristics, none of the variables measuring attitudes toward illness were associated with changes in health status or overall quality of life.

***Physical Outcomes.*** Changes in physical well-being were associated with treatment status,  $F(1,29)=13.00, p=0.001$ . Participants who were in treatment at the start of the 12-week study showed greater improvements in physical well-being than patients not in active treatment. Upon adjusting for treatment status, improved physical well-being was also associated with higher levels of external locus of control,  $F(1,29)=5.65, p=0.024$ . Fewer experienced physical symptoms was predicted by a longer time since diagnosis,  $F(1,29)=10.0, p=0.004$ . Again, after adjustment for time since diagnosis, higher

**Table 1.** Baseline and 12-week follow-up scores across outcome measures by treatment group.

|                                   |                         | Range<br>(min-max) | Control,<br>Baseline-<br>Adjusted<br>Mean<br>(sd) | Treatment,<br>Baseline-<br>Adjusted<br>Mean<br>(sd) | F-Value<br>(adjusting for<br>baseline) | F-Value<br>(adjusting for<br>baseline,<br>participation) |
|-----------------------------------|-------------------------|--------------------|---------------------------------------------------|-----------------------------------------------------|----------------------------------------|----------------------------------------------------------|
| Health-Related<br>Quality of Life | FACT-total              | 61 - 104           | 85.6 (11.8)                                       | 88.2 (11.0)                                         | 1.12 (2,49)                            | 1.01 (4,47)                                              |
|                                   | QOL<br>thermometer      | 30.0 –<br>100.0    | 83.3 (17.1)                                       | 85.2 (9.9)                                          | 0.28 (2,49)                            | 1.22 (4,47)                                              |
| Psychological<br>Well-Being       | FACT EWB                | 5 - 20             | 15.2 (3.6)                                        | 16.4 (2.6)                                          | 3.45 (2,49)†                           | 4.22 (4,47) *                                            |
|                                   | IOES Total              | 0.05 –<br>2.76     | 0.99 (0.7)                                        | 0.93 (0.6)                                          | 0.27 (2,48)                            | 0.43 (4,46)                                              |
|                                   | IOES Intrusion          | 0 – 2.63           | 1.12 (0.7)                                        | 1.07 (0.6)                                          | 0.16 (2,48)                            | 0.12 (4,46)                                              |
|                                   | IOES<br>Avoidance       | 0 – 2.86           | 0.85 (0.7)                                        | 0.70 (0.5)                                          | 1.58 (2,48)                            | 0.09 (4,46)                                              |
|                                   | IOES<br>Hyperarousal    | 0 – 2.83           | 0.98 (0.7)                                        | 1.03 (0.7)                                          | 0.12 (2,48)                            | 1.12 (4,46)                                              |
|                                   | Depression              | 0-9                | 3.34 (2.7)                                        | 2.71 (2.9)                                          | 0.95 (2,49)                            | 0.02 (4,47)                                              |
|                                   | Anxiety                 | 0-19               | 6.37 (4.0)                                        | 6.36 (4.7)                                          | 0.00 (2,49)                            | 2.36 (4,47)                                              |
| Physical Well-<br>Being           | Symptom<br>Prevalence   | 0-24               | 7.79 (6.4)                                        | 7.21 (6.5)                                          | 0.15 (2,57)                            | 0.00 (4,55)                                              |
|                                   | Symptom<br>Frequency    | 1-4                | 2.14 (0.5)                                        | 2.31 (0.6)                                          | 1.15 (2,44)                            | 1.38 (4,42)                                              |
|                                   | Symptom<br>Severity     | 1-4                | 1.81 (0.5)                                        | 1.82 (0.7)                                          | 0.00 (2,42)                            | 0.70 (4,40)                                              |
|                                   | Symptom<br>Bother       | 0-3                | 1.58 (0.8)                                        | 1.46 (0.7)                                          | 0.31 (2,42)                            | 0.93 (4,40)                                              |
|                                   | FACT FWB                | 16-28              | 22.2 (4.2)                                        | 23.4 (4.0)                                          | 1.51 (2,49)                            | 1.76 (4,47)                                              |
|                                   | FACT PWB                | 12-28              | 24.5 (3.2)                                        | 25.2 (2.8)                                          | 0.93 (2,49)                            | 0.64 (4,47)                                              |
|                                   | FACT Breast<br>Cancer   | 9-35               | 24.2 (6.3)                                        | 25.2 (4.9)                                          | 0.80 (2,49)                            | 0.24 (4,47)                                              |
| Social Well-<br>Being             | Number of<br>supports   | 1-30               | 7.63 (4.2)                                        | 9.75 (6.9)                                          | 2.48 (2,48)                            | 1.64 (4,46)                                              |
|                                   | Support<br>Satisfaction | 20.6 - 100         | 82.0 (21.9)                                       | 85.0 (8.9)                                          | 0.57 (2,48)                            | 0.09 (4,46)                                              |
|                                   | FACT SWB                | 11.7-28            | 23.6 (4.8)                                        | 23.3 (4.2)                                          | 0.11 (2,49)                            | 0.35 (4,47)                                              |

\*  $p < 0.05$ , †  $p < 0.10$

levels of external locus of control predicted a reduction in the number of reported physical symptoms,  $F(1,29)=9.12$ ,  $p=0.005$ . Reduced impact of breast-cancer specific symptoms was not associated with any baseline demographic or medical variables but was associated with lower self-efficacy for maintaining activity and independence,  $F(1,26)=4.81$ ,  $p=0.04$ , greater self-efficacy for accepting cancer and maintaining a positive attitude,  $F(1,26)=10.3$ ,  $p=0.004$ , and higher levels of external locus of control,  $F(1,26)=16.8$ ,  $p=0.0004$ .

**Functional Outcomes.** Improved functional well-being was associated with higher annual household income,  $F(1,21)=9.61$ ,  $p=0.005$ . After covarying for the effect of income, greater functional well-being was also predicted by greater external locus of control,  $F(1,21)=8.54$ ,  $p=0.008$ .

**Emotional Outcomes.** Improved emotional well-being was significantly associated with having more nodes with metastatic breast cancer at baseline,  $F(1,26)=5.01$ ,  $p=0.03$ . After adjusting for this effect, lower levels of avoidance coping predicted improved emotional well-being,  $F(1,26)=4.36$ ,  $p=0.047$ . Improved levels of anxiety were associated with having more positive nodes,  $F(1,26)=5.55$ ,  $p=0.026$ . None of the attitudes toward illness predicted changes in anxiety level. Changes in symptoms of depression or total impact of events were not significantly predicted by any of the demographic, medical, or attitudinal factors.

**Social Outcomes.** Improved social and family well-being was associated with less time since diagnosis at entry into the study,  $F(1,24)=7.02$ ,  $p=0.014$ . Upon adjustment for time since diagnosis, self-efficacy for accepting cancer and maintaining a positive attitude was marginally associated with improved social and family well-being,  $F(1,24)=4.06$ ,  $p=0.055$ . Greater perceived available social support was associated with younger age,  $F(1,33)=6.91$ ,  $p=0.013$ . Increased number of available social supports was associated with clinical stage,  $F(1,27)=6.82$ ,  $p=0.0006$ , such that women with clinical stage I breast cancer showed greater improvement than women with stage 0 or 2. After adjusting for clinical stage, lower levels of avoidance coping were associated with more individuals available to provide social support,  $F(1,27)=7.13$ ,  $p=0.013$ .

**Impact of Participation on Outcomes.** LIWC participation variables (i.e., average word count of messages, percentage of words related to emotional processes, and percentage of words related to cognitive processing) were not predictive of changes in outcome. Because participants exhibited considerable variability across messages in message length and use of words related to emotion and cognitive-processing, we chose to analyze the relationships between total *numbers* of words used in each word category rather than *percentage of total words* within each message. This analytic strategy captured more variance in each of the primary outcome measures.

**Quality of Life Outcomes.** Change in self-reported health status was not associated with any of the participation variables. However, increased overall quality of life scores were predicted by higher total length of messages posted to the online group,  $F(1,23)=7.95$ ,  $p=0.01$ , and lower total number of emotion words used over the course of the study,  $F(1,23)=4.30$ ,  $p=0.05$ . The set of participation variables accounted for 69.5% of the total variance in overall quality of life scores.

**Physical Outcomes.** Change in physical well-being scores was associated with higher total message length,  $F(1,23)=6.19$ ,  $p=0.02$ , and lower use of words related to cognitive processes,  $F(1,23)=5.77$ ,  $p=0.02$ . Trends for fewer reported physical symptoms were associated with greater use of the coping exercises,  $F(1,23)=3.22$ ,  $p=0.09$ , and use of fewer words related to emotion,  $F(1,23)=4.04$ ,  $p=0.056$ . The impact of breast cancer-specific symptoms was significantly reduced by greater use of the coping exercises,  $F(1,23)=5.59$ ,  $p=0.027$ . The set of participation variables accounted for 75.2% of the variance in breast-cancer specific symptoms, 68.2% of the variance in total reported symptoms, and 37.8% of the variance in physical well-being.



*Functional Outcomes.* Improved functional well-being was predicted by higher total length of messages posted to the group,  $F(1,23)=7.44$ ,  $p=0.01$ . The set of participation variables accounted for 57% of the variance associated with change in functional well-being.

*Emotional Outcomes.* Reduced total impact of events scores were predicted by greater use of words related to emotion over the course of the study,  $F(1,23)=4.61$ ,  $p=0.043$ . Changes in depression, anxiety, and overall emotional well-being were not associated with any of the participation variables. The participation variables accounted for 74.8% of the variance in impact of events, 48.3% of the variance in depression, 64.1% of the variance in anxiety, and 76.7% of the variance in emotional well-being.

*Social Outcomes.* Improved social and family well-being was predicted by lower use of emotion-related words during the study,  $F(1,23)=5.75$ ,  $p=0.025$ , and a trend for greater length of messages submitted to the group,  $F(1,23)=3.19$ ,  $p=0.088$ . Improved total perceived available social support was also associated with lower use of emotional words,  $F(1,23)=5.82$ ,  $p=0.024$ . The set of participation variables accounted for 68.2% of the variance in social well-being and 87.8% of the variance in perceived social support.

Finally, in order to evaluate the relative contribution of baseline characteristics and participation in the therapy group on changes across outcome measures, the effects of participation on outcome were tested after adjusting for demographic factors, medical characteristics, and attitudes about illness that were previously shown to be significant predictors of outcome. After adjusting for these baseline characteristics, none of the participation variables were significantly associated with improvements in outcome.

#### *Task 6. Dissemination of Research Findings, Months 29-36.*

- a. Multiple manuscripts will be prepared:
  1. A descriptive paper regarding the use of interactive Web programming to provide psychosocial support and information, the collection of psychological data over the Internet, and the establishment of patient referral services to increase patient participation in social support services available in Comprehensive Cancer Centers. (submission to Journal of Psychosocial Oncology)
  2. A paper describing the intervention and initial 6-week follow-up results for primary dependent variables (submission to Health Psychology)
  3. A paper examining inter-correlations between changes in mediating variables and changes in primary dependent variables, including SEM analyses (submission to Psycho-Oncology)
  4. A paper describing results of the 6-month follow-up evaluations (submission to Health Psychology)
- b. Results of the study will be summarized and presented to all participating clinics and hospitals.
- c. Posters will be presented at annual meetings of the Society of Behavioral Medicine and at the event sponsored by the DOD to describe ongoing progress of the study.

#### *Progress Made in Accomplishing Task 6*

With regard to task 6a, three manuscripts have been prepared. The first, titled "Improving the Effectiveness of Adjuvant Psychological Treatment for Women with Breast Cancer: the Feasibility of Providing Online Support," is currently *in press* in the journal Psycho-Oncology. The second, titled "Randomized Controlled Trial of Computer-Facilitated Adjuvant Psychological Therapy for Early-

Stage Breast Cancer,” has been completed and will soon be sent to the journal Health Psychology for consideration for publication. This manuscript is provided in Appendix A. The third, titled “Toward an Understanding of Therapeutic Change in Adjuvant Psychological Therapies for Breast Cancer: Attitudes, Participation in Therapy, and Outcomes,” is currently in revision and will likely be submitted to the journal Behavioral Medicine for consideration for publication. This manuscript is provided in Appendix B. The final manuscript described in the statement of work, which was proposed to analyze 6-month follow-up data, will not be prepared due to poor response rates for these questionnaires.

Results of the study have been provided to all participating clinics and institutions. As a result of these outreach efforts, the predoctoral investigator has recently become involved in ongoing community-based efforts, through the nonprofit Wellness Community in Santa Monica, CA, to provide Internet-based psychological support mechanisms to people living with cancer. The results of the studies supported by this grant award have yielded significant insight into the mechanisms by which such Internet tools can be used to effect psychological healing. Key variables yet to be explored that may significantly effect changes in outcome variables include group size and level of professional facilitation by a trained counselor or health-care professional. The predoctoral investigator will also be involved with the preparation of a grant to provide Internet-based psychological support to children and adolescents diagnosed with cancer and also to their parents. The investigator also plans to provide similar support interventions to cancer populations that have greater quality of life impairment (e.g., metastatic breast cancer, ovarian cancer, and lung cancer).

Finally, with regard to task 6c, the predoctoral investigator presented the findings of the study in a poster presentation titled, “Using the Internet to Provide Adjunctive Psychological Therapy,” at the U.S. Department of Defense Breast Cancer Research Program Era of Hope 2002 meeting in Orlando, Florida. Findings from mediational analyses will be submitted for presentation to the Society of Behavioral Medicine’s Annual Meeting to be held in Baltimore, MD in March, 2004.

**Key Research Accomplishments**

- Completed organization and data entry for time 1 and time 2 questionnaires
- Wrote and compiled a PERL computer program to track participants' postings of text messages to the SURVIVE web site longitudinally and to prepare these postings for analysis using Linguistic Inquiry and Word Count
- Manuscript, entitled "Improving the Effectiveness of Adjuvant Psychological Treatment for Women with Breast Cancer: The Feasibility of Providing Online Support," accepted for publication in *Psycho-Oncology* in March, 2003; currently in press
- Manuscript, entitled "Investigation of the Effects of Gender and Preparation on Quality of Communication in Internet Support Groups," published in *Computers in Human Behavior, Volume 19(3)*, in May, 2003.
- Developed word libraries for cancer-related information to facilitate text analysis of messages submitted to Survive treatment groups. Manuscript titled, "Use of the Internet for Information and Support: Disclosure Among Persons with Breast and Prostate Cancer," completed and submitted to *Health Psychology* in July, 2002. After making requested revisions, the manuscript was resubmitted to the *Journal of Behavioral Medicine* in June, 2003.
- Collaboration with Mitch Golant, Ph.D. of The Wellness Community, and Janine Giese-Davis, Ph.D. and David Spiege., M.D. of Stanford University on the provision and analysis of mechanisms of change in Internet-based support systems for persons living with cancer.
- Principal Investigator's doctoral training is progressing according to the timeline specified by the grant protocol. Specifically:
  - Investigator was granted a Master's degree (M.P.H.) in Health Care Organization and Policy, with a focus on Outcomes Research, by the UAB School of Public Health in December, 2001
  - Investigator was granted a Ph.D. in Clinical (Medical) Psychology by the UAB Graduate School in May, 2003.
  - Investigator completed dissertation, which was approved by the UAB Graduate School in May, 2003.
  - Investigator completed his predoctoral clinical internship year with Dr. David Wellisch, an expert in the psychological aspects of breast cancer and risk for breast cancer, at the UCLA Neuropsychiatric Institute- the final requirement for his doctoral degree from the UAB Department of Psychology.
  - Investigator was recently awarded a two-year post-doctoral fellowship in the UCLA Division of Cancer Prevention and Control beginning 8/1/03.

**Reportable Outcomes. Ongoing dissemination efforts for DAMD17-00-1-0121.****Published Papers**

**Owen, J.E., Klapow, J.C., Roth, D.L., Nabell, L., & Tucker, D.C.** (in press). "Improving the effectiveness of adjuvant psychological treatment for women with breast cancer: the utility of providing online support." *Psycho-Oncology*.

**Owen, J.E., Yarbrough, E.J., Vaga, A., & Tucker, D.C.** (2003). "Investigation of the effects of gender and preparation on quality of communication in Internet support groups." *Computers in Human Behavior*, 19, 259-275.

**Owen, J.E.; Klapow, J.C.; Hicken, B.; and Tucker, D.** (2001). "Psychosocial interventions for cancer patients: Review of outcomes using a three-dimensional model." *Psycho-Oncology*, 10, 218-230.

**Owen, J.E.; Klapow, J.C.; and Casebeer, L.** (2000). "Evaluating the relationship between pain presentation and health-related quality of life in outpatients with metastatic or recurrent neoplastic disease." *Quality of Life Research*, 9, 855-863.

**Papers in Review**

**Owen, J.E., Klapow, J.C., Roth, D.L., & Tucker, D.C.** (in review). "Use of the Internet for information and support: Disclosure among persons with breast and prostate cancer." *Journal of Behavioral Medicine*. (submitted June, 2003).

**Presentations**

**Owen, J.E., Klapow, J.C., & Tucker, D.C.** (September, 2002). "Using the Internet to provide adjunctive psychological therapy." Poster presented at the U.S. Department of Defense Breast Cancer Research Program Era of Hope 2002 Meeting in Orlando, FL on September 28, 2002.

**Owen, J.E.** (October, 2001). "Surfing to Survive." Invited presentation to the UAB Regional Nursing Conference, October 19, 2001.

Richardson, P., **Owen, J.E.**, Oberheu, A.M. (October, 2001). "The UAB Supportive Care Program." Invited presentation to the UAB Regional Nursing Conference, October 18, 2001.

**Funding Applied For**

**Owen, J.E., Giese-Davis, J., Spiegel, D.** (January, 2003). "Text Analysis of Psychological Processes in Breast Cancer." Grant application submitted to the California Breast Cancer Research Program, \$86,339. Notification of intent to fund was made by Walter Price in May, 2003.

## Conclusion

Considerable progress has been made in the third and final year of this award. Progress from the original Statement of Work has realized nearly all of the major tasks outlined in the original statement of work, with a few notable exceptions related to less-than-expected sample size. Recruitment has been lower than was anticipated, but we have obtained a sufficient sample size to complete data analyses. Further, the sample size obtained in this study is similar to sample sizes obtained in other studies of this type (see Lieberman et al., 2003, *Cancer* 97(4):920-5, 2003 Feb 15.) that received substantially greater levels of grant funding. Data collection was finalized this year, and a comprehensive database of outcome variables, questionnaire-derived data, and text-derived data was completed. One manuscript from this project was published this year, another was accepted for publication and is currently in press, and two additional manuscripts will be submitted for publication within the next 2 months to major journals. Results from the project were presented at the September, 2002 Era of Hope meeting, and additional results will very likely be presented at other national behavioral medicine conferences next year.

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**Appendix A.**

Randomized Controlled Trial of Computer-Facilitated Adjuvant Psychological Therapy for Early-Stage Breast Cancer

**Randomized Controlled Trial of Computer-Facilitated  
Adjuvant Psychological Therapy for Early-Stage Breast Cancer**

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**ABSTRACT:**

Internet-based methods for provision of adjuvant psychological therapy to cancer patients hold promise for increasing the impact of psychosocial interventions. The goal of this controlled trial was to examine the effect of a computer-facilitated group therapy on quality of life outcomes in women with early stage breast cancer. Among the 59 women enrolled into the trial, effects of the 12-week treatment were mediated by the degree to which participants used the web site. Treatment, after adjusting for baseline values and level of participation, was associated with improved emotional well-being. Without the use of a professional facilitator, more sophisticated computer-based facilitation programs will be necessary to increase participation in order to improve the efficacy and reach of Internet-based therapies.

**KEY WORDS:** INTERNET, BREAST CANCER, THERAPY, QUALITY OF LIFE, SUPPORT GROUPS

Adjuvant psychological therapy for cancer can significantly improve the well-being of cancer patients across a range of important outcomes. Despite increasing attention to quality of life outcomes for persons with cancer, the impact of psychological treatment programs for cancer patients is attenuated by poor availability and limited accessibility. Additionally, the extensive time requirements necessary for clinicians to develop and provide adjuvant psychological therapy provide further practical constraints on availability (Jacobsen, Meade, Stein, Chirikos, Small, & Ruckdeschel, 2002). Internet-based treatment programs, by increasing both availability and accessibility, have the potential to increase the impact of psychological therapies for cancer patients—as well as a host of other patient populations with medical or psychological disorders or distress. However, the differences between internet-based therapy and face-to-face therapy are substantial, and few studies have examined the efficacy of internet-based adjuvant therapy for improving patient-based outcomes.

Breast cancer is frequently, if not ubiquitously, associated with distress, and may also be accompanied by clinically significant levels of depression and anxiety. Psychosocial treatments are known to reduce distress and improve aspects of quality of life (Andersen, 1992; Compas, Haaga, Keefe, Leitenberg, & Williams, 1998; Fawzy, Fawzy, Arndt, & Pasnau, 1995; Meyer and Mark, 1995; Sheard & Maguire, 1999; Trijsburg, van Knippenberg, & Rijkman, 1992). However, empirically-supported psychosocial treatments for cancer, including breast cancer, are not widely available. In many rural areas and even within National Cancer Institute-designated Comprehensive Cancer Centers in major metropolitan areas, such therapy programs are not routinely offered to patients, in part perhaps, because of the substantial clinician time required and relative dearth of trained psycho-oncology practitioners (Jacobsen et al., 2002). Community-based support groups provide the lion's share of psychosocial care to oncology patients (Coluzzi

et al., 1995). A study recently conducted by Goodwin and colleagues (2002) provides a notable exception, in which a sizable percentage of all eligible patients at several institutions were offered an empirically-supported psychological therapy. However, even when available, patients may not be able to utilize these services due to practical limitations. Barriers to participation include disease progression (Gustafson, Wise, McTavish, Taylor, Wolberg, Stewart et al., 1993), unwillingness to make a commitment to attend regular meetings (Cunningham et al., 1998), and busy home and work schedules (Fukui et al., 2001).

The emergence of internet-based adjuvant psychological therapies has substantially reduced many of these barriers to patient participation (Owen, Klapow, Roth, Nabell, & Tucker, in review). Online groups obviate the need for a physical meeting place and the need for participants to travel from their homes to a central location (Winzelberg, 1997; Weinberg et al., 1995a; Finn, 1995). Thus, many of the patients who are unable to participate in traditional face-to-face support groups- patients who live at great distance from the clinic, who have demanding work hours, who do not have a convenient means of transportation, or who are too fatigued or physically debilitated to travel- might be more likely to participate in internet-based APT. Results from a recent recruitment study suggest that women with breast cancer express higher levels of interest in Internet-based support groups than for face-to-face groups (Owen et al., in review). Internet-based APT enables participants to access services outside of typical clinic hours (Winzelberg, 1997; Weinberg et al., 1995a; Finn, 1995; Weinberg, 1996). Winzelberg (1997) reports that 66% of the messages posted to an online group are sent between 6pm and 7am, suggesting that participants in computer-based support programs have greater flexibility to obtain support or information at convenient times.

Because cancer-related discussion groups and chat rooms are widely available on the Internet, most published studies examining the use of the Internet by cancer patients have relied on correlational or quasi-experimental designs (Klemm, Reppert, & Visich, 1998; Meric, Bernstam, Mirza, Hunt, Ames, & Ross, 2002; Sharf, 1997; Weinberg, Schmale, Uken, & Wessel, 1995; Weinberg, Uken, Schmale, & Adamek, 1995). In one randomized trial in which participants received a computer to connect to a discussion group and information system, patients in a treatment group showed increases in social support but no change in quality of life relative to controls (Gustafson, Hawkins, Pingree, McTavish, Arora, Mendenhall et al., 2001). In addition to providing therapy by computer, the Gustafson et al. (2001) APT differs from previous face-to-face APTs in two key respects. First, efficacious face-to-face APTs for cancer typically use a limited number of structured sessions to develop coping skills and increase self-disclosure (Spiegel, Morrow, Classen, Raubertas, Stott, Mudaliar et al., 1999; cite Helgeson, Kissane, Fawzy, Cunningham). Second, APTs for cancer typically focus on small groups or individuals (Owen, Klapow, Hicken, & Tucker, 2001). Gustafson et al. (2001) provide an extensive array of cancer-related information, an expert-facilitated group discussion board, decision-making tools, and coping advice. However, all participants ( $n = 147$ ) were placed into a single ongoing group, and participants were not guided in the use of the coping advice or decision-making tools. Because face-to-face APT is efficacious for improving patient-based outcomes (Meyer & Mark, 1995; Sheard & Maguire, 1999), it may be important to more closely mimic the design of these treatment programs when developing internet-based therapies in order to significantly increase quality of life for participants.

The goal of the present study was to develop and evaluate a computer-facilitated, internet-based adjuvant psychological treatment program for women with breast cancer. With an

experimental design, we sought to extend the work of previous researchers in this area by utilizing small, closed groups and a 12-week automatically facilitated therapy program based loosely on similar face-to-face treatments. In order to reduce the investment of clinician time, a computerized program was used to automatically prompt participants by e-mail to post messages to their group or to engage in coping-skills training exercises. Consistent with findings from face-to-face therapy programs for cancer patients, we hypothesized that patients randomized to a treatment group would show significantly higher levels of quality of life, lower levels of depression and anxiety, and less frequent and bothersome physical symptoms than patients assigned to a wait-list control condition.

## **Method**

### *Participants*

Women with histologically confirmed breast cancer, stages 0, 1, and 2, were eligible for participation in the study. Women were not excluded on the basis of medical treatment, time since diagnosis, or previous psychiatric problems so that we might obtain results that could be generalized to a larger population of women with breast cancer. Patients who did not have access to the Internet at home or work or who were unwilling to use a public facility (e.g. a library) to access the Internet were excluded from participation. Women with stage III/IV or recurrent breast cancers were offered direct participation in a pilot version of the treatment condition and were not randomized. Participants were recruited through direct patient contact at follow-up appointments to medical oncology clinics, advertisement posters with business-reply postcards placed in exam rooms of the Hematology/ Oncology outpatient clinic of the UAB Kirklin Clinic, advertisement on university websites related to health, community nurse referral,

and local and national media attention given to the study. Upon communicating interest in being enrolled to a clinic research assistant or contacting us by phone, email, or postcard, all potential participants received a telephone call to confirm characteristics of the disease and to administer informed consent. Eligible and interested participants were then enrolled into the study and later received a baseline assessment by mail. Those participants who completed the baseline assessment were randomized into one of two conditions: a waiting list control group and an internet-based adjuvant psychological therapy, called Survive. A more complete description of the recruitment process is described by Owen et al. (in review). Demographic and medical characteristics of the sample are provided in Table 1.

### *Procedures*

In order to form small groups for each condition, participants were recruited in six cohorts of up to 20 patients. To minimize delays and attrition, participants in each cohort were randomized when the cohort size reached 20 or when the first participant in the cohort had been enrolled for approximately 4 weeks. Participants were then randomized using a random number generator to either the wait-list control condition or the Survive treatment program. After 12 weeks, all participants received a follow-up assessment in the mail. Wait-listed participants were then contacted by telephone to verify interest in remaining in the study and were enrolled in the next available treatment group. This procedure resulted in initial treatment group sizes of 5 (cohort 1), 8 (cohort 2), 5 (cohort 3), 7 (cohort 4), 13 (cohort 5), and 12 (cohort 6).

Participants assigned to the Survive treatment group were contacted by e-mail and provided with a password for secure access into the website (<http://health.psy.uab.edu/survive>) and brief instructions for using the website. The Survive website, developed using hyper-text markup language (HTML) and Practical Extraction and Report Language (PERL), offers a



bulletin board for asynchronous group discussion, a searchable dictionary of medical terminology, a searchable database of local and national breast cancer resources and websites, information and coping advice for management of common physical symptoms such as pain and fatigue, a forum for sharing artwork and poetry, and 6 structured coping-skills training exercises. Each coping exercise was designed to be completed by participants over the course of 2 weeks and adapted from structured exercises provided in manuals used by face-to-face APTs (Cunningham, 1992; Fawzy & Fawzy, 1994; Haber, Acuff, Ayers, Lerman Freeman, Goodheart, Kieffer et al., 1995; Kissane & Seddon, 1994; Nezu, Nezu, Friedman, Faddis & Houts, 1998; Spiegel & Spira, 1991). Coping-skills training exercises included identification of active and passive coping styles, communication with family and friends, identification of relationships between stress, emotion, and behavior, stress-management training, assertiveness training, and structured problem-solving training. In order to reduce the time necessary for facilitating the group and to insure consistency across groups, we also developed a series of 39 prompts that were automatically sent by e-mail in regular intervals over the course of the 12-week program. Each prompt summarized a coping-skills training exercise that could be found on the website and requested that participants post a message to the group describing their experience with the training exercise. Thus, treatment groups were facilitated by a computer and not by a live clinician and were monitored without interference by the lead author. When submitting messages to other members of their group, participants were identified only by first name or an alias to protect confidentiality. All responses to the coping modules and interactions between participants were recorded and stored on a secure computer server.

### *Assessments*

*Health-Related Quality of Life.* Health-related quality of life was assessed with the Functional Assessment of Cancer Therapy- Breast Cancer Form (FACT-B) and a quality of life thermometer. The FACT-B is a 27-item questionnaire which utilizes 5-point Likert scales to evaluate overall quality of life and individual domains of that contribute to the overall score: social well-being, physical well-being, emotional well-being, functional well-being, and breast cancer-specific symptoms (Cella et al., 1993; Cella, 1997). This instrument has adequate internal consistency (overall  $\alpha = 0.90$ , subscale  $\alpha$ 's = 0.63 – 0.86) and good concurrent validity with ECOG performance status (Brady, Cella, Bonomi, Tulsky, Lloyd, Deasy et al., 1997). The measure has also been demonstrated to be sensitive to longitudinal change in persons with cancer (Cella, Eaton, Fairclough, Bonomi, Heyes, Silberman et al., 2002; Cella, Hahn, & Dineen, 2002). The “feelings thermometer” is a single-item which asks participants to rate their overall health on a 0-100 scale anchored by the “least desirable state of health you can imagine” and “perfect health.” The measure has good test-retest reliability, concurrent validity, and sensitivity to change (Badia Llach, Herdman, & Schiaffino, 1999; Cranney, Coyle, Pham, Tetroe, Wells, Jolly et al., 2001).

*Psychological Well-Being.* Psychological well-being was assessed using the Hospital Anxiety and Depression Scale (HADS), the Impact of Events scale (IOES), and the emotional well-being subscale (EWB) of the FACT-B. The HADS is a 14-item, self-report measure that provides summary scores for clinical depression and anxiety. The measure was developed for use with medical populations to avoid overestimates of mood disorder from confounding somatic symptoms and has good internal reliability and construct validity for distinguishing between patients with and without clinical mood disorders (Zigmond & Snaith, 1983). The instrument is sensitive to the effects of adjuvant psychological therapy (Cain et al., 1986; Greer et al., 1992).

The IOES is a 22-item, Likert-type scale designed to measure the intrusiveness of cancer-related thoughts and stimuli (Horowitz, Wilner, & Alvarez, 1979). The instrument has good internal consistency (Cronbachs  $\alpha = 0.79-0.92$ ) and has been shown to be sensitive to the effects of psychosocial intervention (Baider et al., 1994; Edgar et al., 1992; Zilberg, Weiss, & Horowitz, 1982).

*Physical Well-Being.* Physical well-being was assessed using the Memorial Symptom Assessment Scale (MSAS), the physical well-being subscale of the FACT-B, and the breast cancer-specific symptom subscale of the FACT-B. The MSAS is a 32-item inventory designed to measure prevalence, frequency, severity, and distress associated with symptoms commonly reported by cancer patients (Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Kiyasa, Sobel, Coyle, Kemeny, Norton, & Scher, 1994). Three primary scales are derived from the MSAS: indices for psychological symptoms, physical symptoms, and global distress. Adequate reliability has been reported (0.835-0.882), and the instrument has both good content and good construct validity. Importantly, the instrument was developed and validated with a population of cancer patients, though it has been successfully used in non-cancer populations as well.

*Social Well-Being.* Social well-being was measured using the Medical Outcomes Study Social Support Survey (MOS-SSS), a 21-item self-report measure that uses 5-point Likert scales to provide indices of tangible support, emotional/informational support, positive social interaction, and affection from others (Sherbourne & Stewart, 1991). The measure has excellent internal consistency (overall  $\alpha = 0.97$ , subscale  $\alpha$ 's = 0.91-0.96) and good criterion validity. This measure was chosen because of its ability to capture mechanisms of support thought to be particularly relevant to cancer patients: emotional, informational, and practical support.

*Psychological Processes.* For the purposes of this study, coping styles were evaluated using the COPE brief form, a 28-item instrument which provides summary scores for avoidant and active coping styles. Adequate reliability and validity have been reported for this instrument specifically in breast cancer patients (Carver, Scheier, & Weintraub, 1989; Carver, Pozo, Harris, Noriega, Scheier, Robinson et al., 1993). Additionally, comfort with the web site and perceived difficulty navigating the site was measured with 30 7-point Likert items adapted from the Web Analysis and Measurement Inventory (WAMMI; Kirakowski, Claridge, & Whitehand, 1998) and 9 open-ended questions open how the web site could be improved.

#### *Data Analysis*

Using SAS version 8.00, general linear modeling was employed for all multivariate analyses of continuous dependent variables except where otherwise noted. Time two scores on outcome variables were analyzed only after adjusting for baseline values. To examine the effect of group size and initial randomization condition on subsequent participation in the groups, data obtained from cross-over control participants were included in the sample. Differences between the control and treatment conditions on non-continuous variables were tested using chi-square frequency analyses.

### **Results**

#### *Participants*

Fifty-nine women with breast cancer agreed to participate in the study, completed the baseline assessment, and were randomized into either the waiting list control group ( $n = 30$ ) or the Internet-based APT ( $n = 29$ ). Three participants originally assigned to the waiting-list control condition and four participants randomized to the treatment condition failed to complete the second assessment. Eighteen participants assigned to the control group crossed-over into a

treatment group after completing both a baseline and 12-week assessment. Demographic characteristics of the participants who completed both assessments are provided in Table 1. There were no significant baseline differences between the two groups for any of the demographic or outcome variables.

#### *Expectations of the Support Group*

At the baseline evaluation, participants reported their preferences for discussion topics in the group and recently experienced physical and psychological symptoms. The most commonly endorsed themes for group discussion were as follows: information about breast cancer (86.7%), feelings and coping techniques (76.7%), meaning of the illness and impact on lifestyle (72.9%), body image (70%), sharing personal stories (68.3%), and future goals (65%). The majority of participants reported that they did not wish to discuss concerns about death and dying, family roles and children, relationships with their partner, or sexual difficulties. When asked whether they wished to use the group to either give or receive help in coping with their cancer, 74.6% ( $n = 44$ ) of participants stated that they would want to both give and receive support. The remainder of the women stated that they would either like to solely provide support to others (23.7%) or solely to receive support from others (1.69%). Participants reported that the most commonly experienced complaints in the week prior to entering the study were fatigue (72%), sadness (60%), irritability (57%), worry (57%), poor concentration (57%), and difficulty sleeping (53%).

#### *Use and Satisfaction with the Survive Web Site*

Follow-up questionnaires asked participants to evaluate different aspects of the web site using a "yes/no" response format. Participants found the coping exercises to be most helpful (68.2%), followed by the support group/bulletin board area of the site (59.1%) and information

about coping with specific symptoms (57.2%). 82% of participants reported that the coping exercises and/or the support group were helpful. Participants averaged 35.5 total log-ins to the web site, 52.2 hits to the bulletin board, 9.5 postings sent to the bulletin board, 73.4 uses of the coping exercises, 3.4 hours spent logged-in to the web site, and 8.2 minutes per session over the course of the 12-week intervention. Use of each component of the intervention over time is displayed in Figure 1. To test the effect of initial group size on participation, total time spent interacting with the web site and use of the coping exercises were regressed onto group size, randomization condition, and the group size/randomization condition interaction.

Randomization condition was significantly related to total time of interaction with the web site,  $F(1,44) = 4.92, p = 0.032$ . The effects of group size ( $p = 0.09$ ) and the group size \* randomization condition ( $p = 0.07$ ) approached statistical significance. When use of the coping-skills training exercises was regressed onto group size, initial randomization condition, and the group size \* randomization interaction, there were significant effects for both group size,  $F(1,44) = 5.29, p = 0.026$ , and randomization condition,  $F(1,44) = 4.44, p = 0.041$ . Additionally, the group size \* randomization interaction term approached statistical significance,  $p = 0.09$ .

Relationships between group size, initial randomization, and subsequent interaction with the web site are shown in Figure 2. Waiting-list control participants who later crossed-over into a treatment group ( $n = 18$ ) did not differ from participants randomized initially into the treatment condition in demographic variables but evidenced significantly lower tangible support, student's  $t = 2.04, p = 0.047$ , and a trend towards more frequent ( $t = 1.69, p = 0.099$ ) and severe ( $t = 1.70, p = 0.097$ ) physical symptoms.

#### *Effect of Intervention on Quality of Life*

Baseline and follow-up scores on measures of quality of life and specific domains of quality of life are provided in Table 3. After adjusting for baseline scores, there were no significant follow-up differences between the waiting-list control group and the intervention group across any of the primary outcome measures. The treatment group did exhibit a trend towards higher scores on the FACT-G emotional well-being subscale,  $F(1,49) = 3.45, p = 0.07$ . Because use of the web site varied substantially among the participants assigned to the treatment group, the number of time participants accessed the coping exercises on the web site and total time spent using the web site were included as additional covariates. Again, there were no significant group differences for overall quality of life, perceived health status, number of reported physical symptoms, physical well-being, functional well-being, or social well-being. However, the treatment group exhibited significantly higher follow-up scores for emotional well-being than did the control group,  $F(1, 47) = 4.22, p = 0.047$ . Among all participants who were provided with access to the treatment condition, including those initially randomized into the treatment group and those who crossed-over into a treatment group at the time 2 assessment, participation was associated with improvements over time. After adjusting for the assessment immediately prior to beginning a treatment group, total time spent interacting with the web site was associated with reduced total IOES scores,  $F(1,35) = 4.92, p = 0.033$  and IOES avoidance,  $F(1,35) = 4.59, p = 0.039$ . Time of interaction with the treatment group was also associated with trends for reduced IOES hyperarousal,  $F(1,35) = 3.57, p = 0.067$ , reduced HADS depression scores,  $F(1,36) = 3.38, p = 0.074$ , reduced HADS anxiety scores,  $F(1,36) = 3.42, p = 0.072$ , greater use of approach-coping,  $F(1,38) = 4.01, p = 0.052$ , and greater emotional support,  $F(1,38) = 4.05, p = 0.051$ .

#### *Predictors of Participation in the Treatment Group*

Baseline characteristics of participants assigned to the treatment group were correlated with subsequent participation in the group. Having lower functional status ( $r = -0.43$ ,  $p = 0.03$ ) was associated with spending more time interacting with the web site. Greater frequency ( $r = 0.41$ ,  $p = 0.04$ ), severity ( $r = 0.43$ ,  $p = 0.043$ ), distress ( $r = 0.56$ ,  $p = 0.008$ ) of physical symptoms were associated with more active use of the coping skills-training exercises.

### Discussion

As reported elsewhere (Owen et al., in review), recruitment rates in this trial were high overall and particularly high for patients with access to the Internet. Importantly, only a small percentage of the participants were involved in a support group at the time of study entry, suggesting that this Internet-based group improved the accessibility of supportive care options to this patient population. Many participants expressed difficulty finding or being able to attend support services in their home communities, and average travel time to receive medical care for their breast cancer was over 1 hour. However, participants in the trial were younger, wealthier, better educated, and racially more homogenous than would be a random sample of breast cancer patients in this geographic area. These demographic trends highlight the importance of providing supportive care to patients who may have both a high level of need and great difficulty accessing these services. While Internet-based APT may expand the overall reach and impact of supportive care treatments, innovative approaches for reaching underserved populations are of great importance.

The effect of the computer-facilitated support group intervention on patient-based outcomes was mediated by the degree to which participants completed coping-skills training exercises and posted messages to other participants. Participants randomized into the computer-based APT who also actively participated in one of the online groups showed significantly



improved emotional well-being over the course of the trial. However, the effect size is small, and the clinical relevance is likely to be small as well. Additionally, the treatment did not result in improvements across all other measured outcomes. However, in the uncontrolled analyses of change scores in the larger sample of treatment and cross-over participants, participation was linked with a number of benefits in outcome, including reduced intrusiveness of cancer-related thoughts and stimuli and reduced anxiety and depression. These results are notable because they suggest that treatment effects can be improved if greater participation, through messages to other group members, increased emotional expression, or use of the coping-skills training modules, is facilitated.

Importantly, active interaction with the web site was somewhat lower than anticipated. Average time spent interacting with the web site was substantially lower than time of involvement for participants in face-to-face groups. Participants initially randomized into the waiting-list control condition spent an average of nearly 4 hours on the web site, whereas participants initially randomized into the treatment group spent just over 2 hours on the web site. We hypothesize three potential reasons for lower than expected group interaction. First, the effect of group size on subsequent involvement may be quite different for computer-based and face-to-face groups. Computer-based groups may require larger group sizes due to communication that is spread over longer periods of time and the presence of group members who read messages but remain invisible to other members. Second, participants reported few bothersome quality of life impairments prior to starting their involvement in a group. Those participants who crossed-over from the control group into a therapy group were more likely to have lower health status and social support and were more active participants in their groups. Thus, as noted by others, provision of APT to patients with poorer quality of life may be

particularly helpful (Andersen, 1992). Third, automatic facilitation of groups by computer-generated prompts appeared to be of limited effectiveness. Feedback from participants suggested that although the coping-skills training exercises were useful, prompts to interact with exercises were deemed to be overly intrusive and may have discouraged participants from becoming more active in the support group component of the intervention.

Several limitations of this study are noteworthy. Most importantly, the relatively small sample size limits the power to detect potential group differences across outcome measures. Additionally, the sample include women with stage 0, 1, and 2 breast cancers. Even within this population of women with good or excellent prognosis, psychological needs may be quite distinct. Although the need for care is prevalent among women at each stage of disease progression, treatments may need to be tailored to reflect the unique needs of women in each stage. Women with more advanced disease were not evaluated in the trial but may have even greater needs for APT. Supportive services for women with special palliative needs are likely to be underutilized because of patients' health status and difficulty traveling. If groups can be established among women with similar clinical stage and prognosis, social environments may be more conducive to "upward affiliation" – the identification and imitation of someone who is coping well with the disease given similar circumstances (Stanton, Danoff-Burg, Cameron, Snider, & Kirk, 1999). Future attempts to provide supportive services, in traditional settings or through evolving cyber-medicine media, will benefit from addressing the unique needs of women with advanced disease.

The results of this study are encouraging because they demonstrate benefits to emotional well-being. Equally important, however, the results also highlight areas of future work that could increase the efficacy of Internet-based APT. Efficacy of the computer-based facilitation

could be improved by developing simple artificial intelligence programs that could use text analysis to recognize themes of discussion (e.g. alterations of body image, concerns about dying) and to tailor prompts to the individual needs of participants. Computerized prompts could also be designed to mimic, as closely as possible, the verbalizations of professional group facilitators. Additional research will also be necessary to determine the effect of group size on emotional expression and outcome. Further, controlled studies of Internet-based coping groups will make it possible to track which coping-skills training exercises are most commonly used and/or associated with improvements in outcome measures.

Internet-based APT reduces distress for some women with early-stage breast cancer. However, professional group facilitation and individually-tailored therapies remain the gold standard for psychosocial intervention. Because the psychological impact of breast cancer on patients and families is great, expanding access and availability of APT represents an important public health problem. Given the tremendous potential of Internet-based methods, much greater funding for translational research could make support services available to all in need.

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#### Author Note

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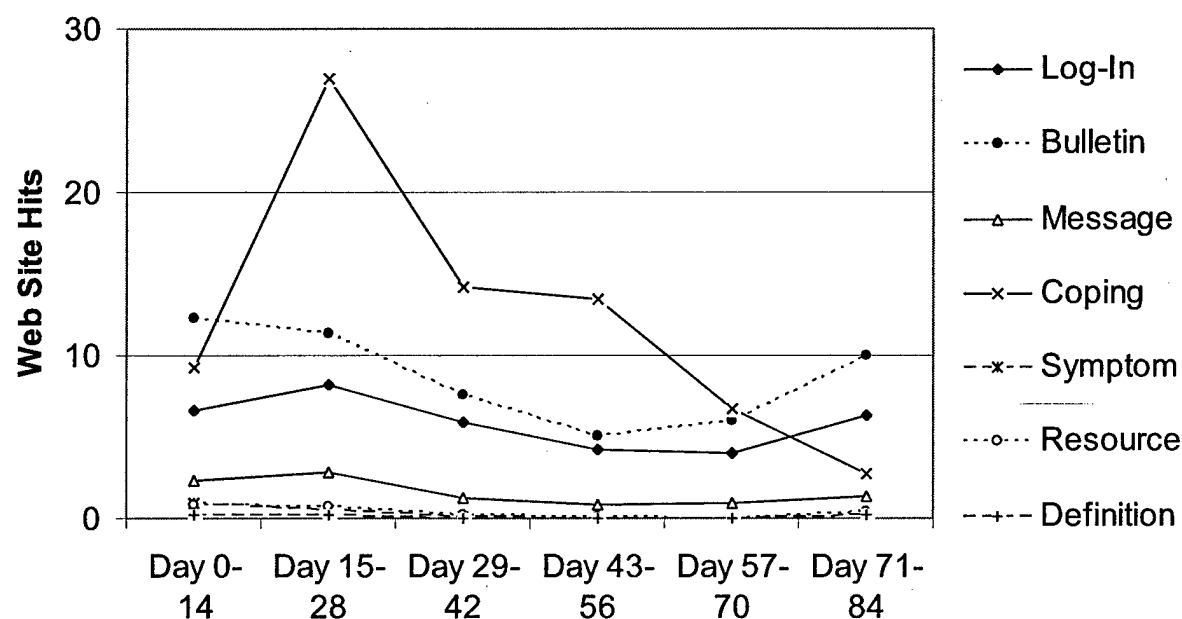
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Table 1. Demographic characteristics of participants.

|                                      | Control Group<br>(n=27) | Treatment Group<br>(n=25) | p-Value   |
|--------------------------------------|-------------------------|---------------------------|-----------|
| Age (years)                          | 51.3                    | 52.5                      | 0.68 n.s. |
| Median Annual Household Income       | 65,000                  | 65,000                    | 0.17 n.s. |
| Education (\$)                       | 15.3                    | 15.8                      | 0.33 n.s. |
| Race (% White)                       | 100                     | 95.8                      | 0.28 n.s. |
| Marital Status (% Married)           | 77.8                    | 87.5                      | 0.46 n.s. |
| Cancer Stage                         |                         |                           | 0.59 n.s. |
| • Stage I (%)                        | 33.3                    | 25.0                      |           |
| • Stage II (%)                       | 40.7                    | 45.8                      |           |
| Time Since Diagnosis (Months)        | 31.8                    | 23.2                      | 0.37 n.s. |
| Distance To Clinic (Miles)           | 55.2                    | 107.5                     | 0.40 n.s. |
| Taking Prescription Medications for: |                         |                           |           |
| • Depression (%)                     | 37.0                    | 54.2                      | 0.22 n.s. |
| • Anxiety (%)                        | 14.8                    | 12.5                      | 0.81 n.s. |
| • Pain (%)                           | 7.4                     | 8.3                       | 0.90 n.s. |

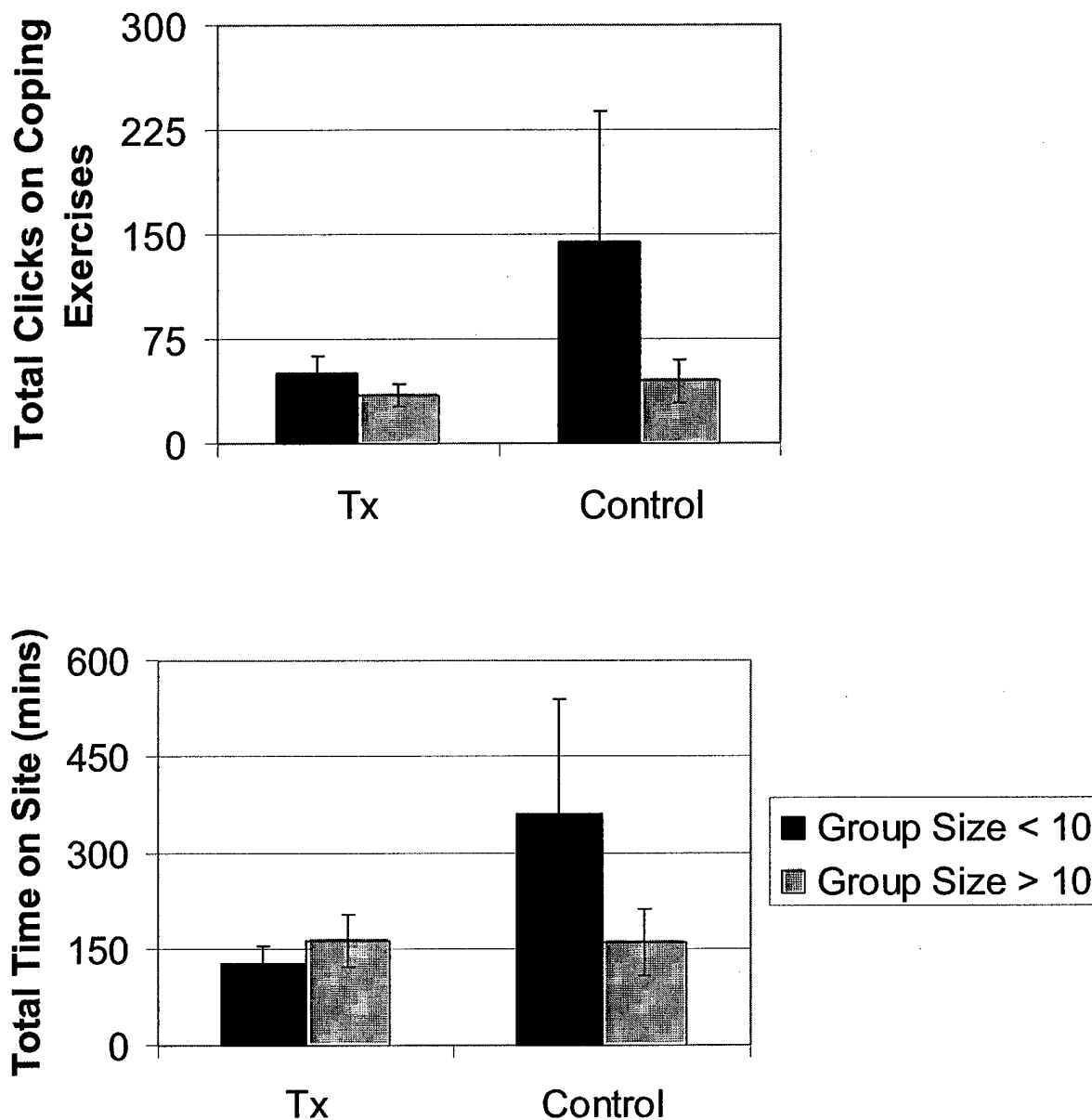
n.s. = no significant difference at the  $p < 0.05$  level.

**Figure 1.** Use of the SURVIVE web site over the course of the 12-week intervention study by women initially randomized into the treatment group (n = 30) and women assigned to the waiting list-control who later crossed-over into a treatment group (n = 18).





**Figure 2.** Relationships between group size, randomization condition, and subsequent participation in the web support group.



**Table 3.** Baseline and 12-week follow-up scores across outcome measures by treatment group.

|                                          |                         | Range<br>(min-<br>max) | Control,<br>Baseline-<br>Adjusted<br>Mean<br>(sd) | Treatment,<br>Baseline-<br>Adjusted<br>Mean<br>(sd) | F-Value<br>(adjusting<br>for baseline) | F-Value<br>(adjusting for<br>baseline,<br>participation) |
|------------------------------------------|-------------------------|------------------------|---------------------------------------------------|-----------------------------------------------------|----------------------------------------|----------------------------------------------------------|
| Health-<br>Related<br>Quality of<br>Life | FACT-total              | 61 - 104               | 85.6 (11.8)                                       | 88.2 (11.0)                                         | 1.12 (2,49)                            | 1.01 (4,47)                                              |
|                                          | QOL<br>thermometer      | 30.0 -<br>100.0        | 83.3 (17.1)                                       | 85.2 (9.9)                                          | 0.28 (2,49)                            | 1.22 (4,47)                                              |
| Psychological<br>Well-Being              | FACT EWB                | 5 - 20                 | 15.2 (3.6)                                        | 16.4 (2.6)                                          | 3.45 (2,49)†                           | 4.22 (4,47) *                                            |
|                                          | IOES Total              | 0.05 -<br>2.76         | 0.99 (0.7)                                        | 0.93 (0.6)                                          | 0.27 (2,48)                            | 0.43 (4,46)                                              |
|                                          | IOES<br>Intrusion       | 0 - 2.63               | 1.12 (0.7)                                        | 1.07 (0.6)                                          | 0.16 (2,48)                            | 0.12 (4,46)                                              |
|                                          | IOES<br>Avoidance       | 0 - 2.86               | 0.85 (0.7)                                        | 0.70 (0.5)                                          | 1.58 (2,48)                            | 0.09 (4,46)                                              |
|                                          | IOES<br>Hyperarousal    | 0 - 2.83               | 0.98 (0.7)                                        | 1.03 (0.7)                                          | 0.12 (2,48)                            | 1.12 (4,46)                                              |
|                                          | Depression              | 0-9                    | 3.34 (2.7)                                        | 2.71 (2.9)                                          | 0.95 (2,49)                            | 0.02 (4,47)                                              |
|                                          | Anxiety                 | 0-19                   | 6.37 (4.0)                                        | 6.36 (4.7)                                          | 0.00 (2,49)                            | 2.36 (4,47)                                              |
| Physical Well-<br>Being                  | Symptom<br>Prevalence   | 0-24                   | 7.79 (6.4)                                        | 7.21 (6.5)                                          | 0.15 (2,57)                            | 0.00 (4,55)                                              |
|                                          | Symptom<br>Frequency    | 1-4                    | 2.14 (0.5)                                        | 2.31 (0.6)                                          | 1.15 (2,44)                            | 1.38 (4,42)                                              |
|                                          | Symptom<br>Severity     | 1-4                    | 1.81 (0.5)                                        | 1.82 (0.7)                                          | 0.00 (2,42)                            | 0.70 (4,40)                                              |
|                                          | Symptom<br>Bother       | 0-3                    | 1.58 (0.8)                                        | 1.46 (0.7)                                          | 0.31 (2,42)                            | 0.93 (4,40)                                              |
|                                          | FACT FWB                | 16-28                  | 22.2 (4.2)                                        | 23.4 (4.0)                                          | 1.51 (2,49)                            | 1.76 (4,47)                                              |
|                                          | FACT PWB                | 12-28                  | 24.5 (3.2)                                        | 25.2 (2.8)                                          | 0.93 (2,49)                            | 0.64 (4,47)                                              |
|                                          | FACT Breast<br>Cancer   | 9-35                   | 24.2 (6.3)                                        | 25.2 (4.9)                                          | 0.80 (2,49)                            | 0.24 (4,47)                                              |
|                                          | Number of<br>supports   | 1-30                   | 7.63 (4.2)                                        | 9.75 (6.9)                                          | 2.48 (2,48)                            | 1.64 (4,46)                                              |
|                                          | Support<br>Satisfaction | 20.6 -<br>100          | 82.0 (21.9)                                       | 85.0 (8.9)                                          | 0.57 (2,48)                            | 0.09 (4,46)                                              |
| Social Well-<br>Being                    | FACT SWB                | 11.7-28                | 23.6 (4.8)                                        | 23.3 (4.2)                                          | 0.11 (2,49)                            | 0.35 (4,47)                                              |

\*  $p < 0.05$ , †  $p < 0.10$

**Appendix B.**

**Toward an Understanding of Therapeutic Change in Adjuvant Psychological Therapies  
for Breast Cancer: Attitudes, Participation in Therapy, and Outcomes**

**Toward an Understanding of Therapeutic Change in Adjuvant Psychological Therapies  
for Breast Cancer: Attitudes, Participation in Therapy, and Outcomes**

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**ABSTRACT:**

Psychosocial interventions to treat distress associated with the diagnosis of cancer have been shown to improve patient outcomes across a variety of domains, yet little is known about how such treatments bring about therapeutic change. This study evaluated factors associated with clinical improvement in fifty-nine women with early-stage breast cancer who participated in a computer-facilitated adjuvant psychological therapy via the internet. Demographic factors, medical characteristics, attitudes about illness, and degree of participation in the therapy program were used as predictors of physical, emotional, social, functional, and quality of life outcomes. Statistically significant improvements were associated with higher levels of physical distress at baseline, external health-related locus of control, approach coping, use of online coping skills-training exercises, and quality of messages submitted to the online group. Implications for future psychosocial interventions for cancer are explored.

**KEY WORDS:** BREAST CANCER, INTERNET, PSYCHOLOGICAL THERAPY, QUALITY OF LIFE, PARTICIPATION

## **Introduction**

As a means of increasing the public health impact of psychological therapies provided to persons experiencing distress secondary to cancer diagnosis, treatment, and survival, Internet-based methods have shown remarkable promise for improving emotional well-being of patients and providing highly sought-after information. Use of Internet-based adjuvant psychological therapies, by recording every interaction between the therapist and patient, also provides a unique opportunity to evaluate the effect of the therapy on the patient's behavior and, more importantly, the relationship between the patient's behavior and clinically meaningful outcomes. We have previously described outcomes associated with participation in a computer-based therapy group for women with early stage breast cancer (Owen, Klapow, Roth, Shuster, Bellis, Meredith, & Tucker, in review). The purpose of this study is to characterize the interactive behavior of participants in this computerized adjuvant psychological therapy and to examine the relationship between this behavior and subsequent outcomes.

Women with breast cancer frequently turn to the support of other women facing similar difficulties for assistance in coping with adjustment to the disease, and adjuvant psychological therapies have been shown to significantly improve quality of life for women who participate in these programs. Recently, Giese-Davis, Koopman, Butler, Classen, Cordova, Fobair et al. (2002) have suggested that supportive-expressive group therapy reduces the suppression of negative emotional experiences among women with breast cancer and that this process may be key to obtaining clinical benefit. However, little is known about the relationship between emotional expression and subsequent clinical changes for participants in adjuvant psychological therapies. Traditionally, researchers have relied on questionnaires to determine the mechanisms by which psychological therapies related to changes in outcome. Internet-based therapies, by cataloguing written exchanges between group members, offer the additional opportunity to examine word choice as measure of psychological processes that may be associated with outcome.

Whereas the mechanisms by which emotional and cognitive processing may influence health outcomes are poorly understood, these findings are robust with respect to persons with cancer. A large, though controversial, body of literature suggests that emotional suppression may be related to progression of cancer (Gross, 1989; Temoshok, 1987). Adjuvant psychological therapies are often designed to promote emotional expression among women with breast cancer, and degree of involvement or psychological "work" in such groups is thought to be associated with improved emotional well-being (Cunningham et al., 2000; Montazeri et al., 2001). Classen et al. (1996) report that emotional expressiveness among participants in a supportive-expressive therapy group is associated with less severe mood disturbance among women with breast cancer. More recently, Stanton et al. (2000) report evidence that emotional

expression is associated with lower health-care resource utilization, higher levels of overall health, and lower distress over time among breast cancer patients.

Because internet-based therapies require participants to write about their personal experiences associated with cancer, such therapies have much in common with expressive writing interventions pioneered by James Pennebaker (Petrie, Booth, & Pennebaker, 1998; Richards, Beal, Seagal, & Pennebaker, 2000). Expressive writing interventions have shown early promise in medical populations for yielding positive health outcomes (Smyth, Stone, Hurewitz, & Kaell, 1999). However, expressive writing in breast cancer patients has yielded mixed results to date. In one study no changes in distress were evident through 28 weeks of follow-up, whereas a second study reports reduced physical symptoms and health-care utilization (Stanton, Danoff-Burg, Cameron, Collins, Sworowski, & Kirk; 1999; Walker, Nail, & Croyle, 1999). Stanton and colleagues (2002) have shown that written emotional disclosure in women with breast cancer is associated with improvements in physical symptoms and for some women, improvements in psychological well-being.

Common to many of the expressive writing interventions are findings that content of the writing is correlated with its impact on psychological and physical health outcomes. Improved health is ascribed to three linguistic patterns: 1) high use of positive emotion words (e.g. happy, joyful), 2) moderate use of negative emotion words (e.g. sad, angry), and 3) increasing use of causal and insight words (e.g. because, therefore; Esterling, L'Abate, Murray, & Pennebaker, 1999). Pennebaker and Francis (1999) developed the Linguistic Inquiry and Word Count (LIWC) program to measure the use of these and other categories of words in order to evaluate the relationship between psychological processes, associated with word choice, and outcomes. In the two expressive writing interventions conducted with cancer patients, evidence of increased



emotional and cognitive processing relative to control participants is reported (Stanton, Danoff-Burg, Cameron, Collins, Sworowski, & Kirk; 1999; Walker, Nail, & Croyle, 1999). However, efforts to examine psychological processes of women undergoing adjuvant psychological therapy have been limited in scope. Previous researchers have relied upon qualitative methods to examine the degree of participants' involvement in therapy (Klemm, Hurst, Dearholt, & Trone, 1999; Cunningham et al., 2000). After reviewing participants' expressions in a therapy group, Cunningham et al. (2000) classified degree of involvement as "high, moderate, or low." Examination of word choice and online behavior in an Internet-based psychological therapy allows for an improved capacity to quantify participation in treatment.

As described by Owen et al. (2001), relatively few studies of adjuvant psychological therapies for cancer have measured or examined potential mechanisms of action. By measuring these variables, it becomes possible to evaluate possible associations between components of the therapy (e.g. facilitating supportive interactions among group members, encouraging emotional expression, or reinforcing concrete problem-solving skills) and subsequent improvements in quality of life. Previous studies have examined psychological mechanisms of action that include locus of control, coping, knowledge about chemotherapy, self-efficacy and perceived health<sup>23-24</sup>. Telch and Telch (1986) demonstrated that psychological treatment for cancer patients resulted in significantly improved self-efficacy for coping with the disease. Similarly, ego strength predicts lower levels of depression in cancer patients (Edgar, Rosberger, & Nowlis, 1992). In a study of patients with malignant melanoma, avoidant forms of coping were shown to be associated with higher levels of anxiety, depression, fatigue, and anger, whereas active coping was associated with lower levels of anger (Fawzy, Cousins, Fawzy, Kemeny, Elashoff, & Morton, 1990).

#### *Goals of this Study*

The goals of the present study are to three-fold. First, we sought to examine the relationship between attitudes about illness and changes in clinical outcome among participants in an Internet-based adjuvant psychological therapy for breast cancer. Second, we sought to determine whether use of therapeutic coping skills-training exercises, time spent interacting on the web site, and word choice in messages sent to the online support group were predictive of changes in clinical outcome. Third, we explored demographic and attitudinal factors that were associated with participation in the Internet-based therapy group. To address these goals, the following hypotheses were evaluated: 1) greater participation in the therapy group and higher use of words related to affect and cognitive processing would be associated with clinical benefit; and 2) active coping and greater self-efficacy for managing cancer-related problems would be associated with both participation in the online group and improvements in quality of life.

## **Method**

### *Participants*

All women with histologically confirmed breast cancer were eligible for participation in this study. Women with clinical stage 0, 1, or 2 breast cancer (early stage) were invited to participate in a randomized controlled trial of an Internet-based therapy group. Women with more advanced disease, clinical stage 3 or 4 (late stage), were invited to join an Internet-based therapy group without taking part in the randomized trial. Participants were recruited during outpatient visits to the UAB Comprehensive Cancer Center. Additional information about the recruitment process is described elsewhere (Owen et al., in review).

### *Procedures*

In order to form small groups for each condition, participants were recruited in six cohorts of up to 20 patients. To minimize delays and attrition, early stage participants in each

cohort were randomized when the cohort size reached 20 or when the first participant in the cohort had been enrolled for approximately 4 weeks. Early stage participants were randomized using a random number generator to either the wait-list control condition or the Survive treatment program. Wait-listed early stage participants were then contacted by telephone to verify interest in remaining in the study and were enrolled in the next available treatment group. This procedure resulted in an average initial treatment group size of 8.3 for women with early stage disease. Late stage participants were not randomized or placed on waiting-lists and were enrolled into a treatment group as soon as enough participants had enrolled to form a viable group. This procedure resulted in an average starting group size of 6.5.

Once placed in a therapy group, participants were contacted by e-mail and provided with a password for secure access into the website (<http://health.psy.uab.edu/survive>) and brief instructions for using the website. The website provides a bulletin board for asynchronous group discussion, a searchable dictionary of medical terminology, a searchable database of local and national breast cancer resources and websites, information and coping advice for management of common physical symptoms such as pain and fatigue, a forum for sharing artwork and poetry, and 6 structured coping-skills training exercises. Each coping exercise was designed to be completed by participants over the course of 2 weeks and adapted from structured exercises provided in manuals used by face-to-face APTs (Cunningham, 1992; Fawzy & Fawzy, 1994; Haber, Acuff, Ayers, Lerman Freeman, Goodheart, Kieffer et al., 1995; Kissane & Seddon, 1994; Nezu, Nezu, Friedman, Faddis & Houts, 1998; Spiegel & Spira, 1991). Coping-skills training exercises included identification of active and passive coping styles, communication with family and friends, identification of relationships between stress, emotion, and behavior, stress-management training, assertiveness training, and structured problem-solving training. A

series of 39 e-mail prompts were sent in regular intervals, averaging once every 2.2 days, over the course of the 12-week program. Each prompt summarized a coping-skills training exercise that could be found on the website and asked participants to review the exercise at their convenience. Thus, treatment groups were facilitated by a computer and not by a live clinician and were monitored without interference by the lead author. When submitting messages to other members of their group, participants were identified only by first name or an alias to protect confidentiality. All responses to the coping modules and interactions between participants were recorded and stored on a secure computer server.

### *Assessments*

*Health-Related Quality of Life.* Health-related quality of life was assessed with the Functional Assessment of Cancer Therapy- Breast Cancer Form (FACT-B) and a quality of life thermometer. The FACT-B is a 27-item questionnaire which utilizes 5-point Likert scales to evaluate overall quality of life and individual domains that contribute to the overall score: social well-being, physical well-being, emotional well-being, functional well-being, and breast cancer-specific symptoms (Cella, 1997). This instrument has adequate internal consistency (overall  $\alpha = 0.90$ , subscale  $\alpha$ 's = 0.63 – 0.86) and good concurrent validity with ECOG performance status (Brady, Cella, Bonomi, Tulskey, Lloyd, Deasy et al., 1997). The measure has also been demonstrated to be sensitive to longitudinal change in persons with cancer (Cella, Eaton, Fairclough, Bonomi, Heyes, Silberman et al., 2002; Cella, Hahn, & Dineen, 2002). The “feelings thermometer” is a single-item which asks participants to rate their overall health on a 0-100 scale anchored by the “least desirable state of health you can imagine” and “perfect health.” The measure has good test-retest reliability, concurrent validity, and sensitivity to change (Badia Llach, Herdman, & Schiaffino, 1999; Cranney, Coyle, Pham, Tetroe, Wells, Jolly et al., 2001).

*Psychological Well-Being.* Psychological well-being was assessed using the Hospital Anxiety and Depression Scale (HADS), the Impact of Events scale (IOES), and the emotional well-being subscale (EWB) of the FACT-B. The HADS is a 14-item, self-report measure that provides summary scores for clinical depression and anxiety. The measure was developed for use with medical populations to avoid overestimates of mood disorder from confounding somatic symptoms and has good internal reliability and construct validity for distinguishing between patients with and without clinical mood disorders (Zigmond & Snaith, 1983). The instrument is sensitive to the effects of adjuvant psychological therapy (Cain et al., 1986; Greer et al., 1992). The IOES is a 22-item, Likert-type scale designed to measure the intrusiveness of cancer-related thoughts and stimuli (Horowitz, Wilner, & Alvarez, 1979). The instrument has good internal consistency (Cronbachs  $\alpha = 0.79-0.92$ ) and has been shown to be sensitive to the effects of psychosocial intervention (Baider et al., 1994; Edgar et al., 1992; Zilberg, Weiss, & Horowitz, 1982).

*Physical Well-Being.* Physical well-being was assessed using the Memorial Symptom Assessment Scale (MSAS), the physical well-being subscale of the FACT-B, and the breast cancer-specific symptom subscale of the FACT-B. The MSAS is a 32-item inventory designed to measure prevalence, frequency, severity, and distress associated with symptoms commonly reported by cancer patients (Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Kiyasa, Sobel, Coyle, Kemeny, Norton, & Scher, 1994). Three primary scales are derived from the MSAS: indices for psychological symptoms, physical symptoms, and global distress. Adequate reliability has been reported (0.835-0.882), and the instrument has both good content and good construct validity. Importantly, the instrument was developed and validated with a population of cancer patients, though it has been successfully used in non-cancer populations as well.

*Social Well-Being.* Social well-being was measured using the Medical Outcomes Study Social Support Survey (MOS-SSS), a 21-item self-report measure that uses 5-point Likert scales to provide indices of tangible support, emotional/informational support, positive social interaction, and affection from others (Sherbourne & Stewart, 1991). The measure has excellent internal consistency (overall  $\alpha = 0.97$ , subscale  $\alpha$ 's = 0.91-0.96) and good criterion validity. This measure was chosen because of its ability to capture mechanisms of support thought to be particularly relevant to cancer patients: emotional, informational, and practical support.

*Psychological Processes.* For the purposes of this study, coping styles were evaluated using the COPE brief form, a 28-item instrument which provides summary scores for avoidant and active coping styles. Adequate reliability and validity have been reported for this instrument specifically in breast cancer patients (Carver, Scheier, & Weintraub, 1989; Carver, Pozo, Harris, Noriega, Scheier, Robinson et al., 1993). Self-efficacy for managing cancer-related problems was assessed using the Cancer Behavior Inventory Brief Form (CBI-B; Merluzzi & Martinez Sanchez, 1997). This scale utilizes twelve 9-point Likert-type items to assess patients' confidence in their ability to maintain independence, cope with side-effects, accept their cancer, seek out medical information, regulate emotions, and seek support. The CBI-B has good reliability ( $\alpha = 0.85$ ) and construct validity (Merluzzi, Nairn, Hegde, Martinez Sanchez, & Dunn, 2001). The Multidimensional Health Locus of Control scale (MHLC) was used to measure the extent to which participants believed they could themselves exert control their disease (internal locus of control) or relied upon others, such as physicians, to do so (external locus of control; Wallston, Stein, & Smith, 1994). The MHLC has been widely used in cancer populations and has good reliability and validity (Andrykowski & Brady, 1994; Baider, Uziely, & DeNour, 1994; Malceme, Compas, Epping-Jordan, & Howell, 1995).

*Participation Variables.* Discuss coping hits, session time, and LIWC variables.

### *Data Analysis*

All data analyses were employed using SAS version 8.00. In order to reduce the number of outcome variables examined and limit the probability of committing a type II error, factor-based scores for all primary outcome domains were generated by converting each variable into a z-score and summing the variables for each domain. This process resulted in five factor-based outcome variables: quality of life (calculated by summing standardized scores for the FACT-B total score and the quality of thermometer rating), physical outcomes (summed standardized scores for FACT physical well-being and MSAS total number of reported physical symptoms), functional outcomes (standardized score for FACT functional well-being scale), emotional outcomes (summed standardized scores for FACT emotional well-being, HADS anxiety, HADS depression, and IOES total score), and social outcomes (summed standardized scores for FACT social well-being, MOS-SSS number of supports, and MOS-SSS total score).

### **Results**

*Participants.* Participants included 59 women with early-stage breast cancer. Demographics characteristics of the participants are shown in Table 1. Among the 59 early-stage participants, 7 (11.9 %) never logged in to the web site or otherwise participated in the support group. Among the 52 participants active in the therapy group, 36 (69.2%) completed the 12-week follow-up assessment. Relative to the women who completed the 12-week therapy group, the 16 participants who were lost to follow-up were significantly younger,  $t(56) = 2.93$ ,  $p < 0.01$ , exhibited more breast-cancer specific symptoms on the FACT-B,  $t(55) = 2.35$ ,  $p = 0.022$ , and perceived fewer positive contributions associated with cancer,  $t(55) = 2.27$ ,  $p = 0.027$ .

**Changes Over Time.** Repeated measures analysis of variance was employed to test whether quality of life, physical, functional, emotional, and social outcomes exhibited change over time. Significant effects of time were observed for total FACT score,  $F(1,34) = 5.15$ ,  $p = 0.03$ , functional well-being,  $F(1,34) = 6.51$ ,  $p = 0.015$ , frequency of physical symptoms,  $F(1,31) = 5.23$ ,  $p = 0.029$ , and emotional well-being,  $F(1,34) = 4.82$ ,  $p = 0.035$ . Participants completing the 12-week therapy program demonstrated improved total FACT scores, functional well-being, and emotional well-being. However, frequency of reported physical symptoms increased over the course of the intervention.

To calculate change over time in word choice within messages posted to the online support group, messages were categorized into three time intervals: within the first 4 weeks of the group, between weeks 4 and 8, and between weeks 8 and 12. All messages posted within a given interval were averaged to determine an interval average for each participant. For individuals who participated in the group but did not post messages during one of the time intervals, missing data were replaced with group means in order to assess change over time. For number of words contained within each message, there was no significant change over time. Messages, on average over the course of the study, contained 316.3 words in total. There were significant changes over time in use of words related to cognitive processing,  $F(2,116) = 4.36$ ,  $p = 0.0156$ , emotion,  $F(2,116) = 16.31$ ,  $p < 0.0001$ , and cancer,  $F(2,116) = 4.68$ ,  $p = 0.0127$ . Participants exhibited increasing use of words related to cognitive processing and emotion and decreasing use of words related to cancer (see Table 2). Participants also exhibited significant decreases over time in logins to the website,  $F(2,116) = 12.98$ ,  $p < 0.0001$ , use of the coping exercises,  $F(2,116) = 13.22$ ,  $p < 0.0001$ , use of the bulletin board,  $F(2,116) = 14.04$ ,  $p < 0.0001$ , and number of messages sent to the bulletin board,  $F(2,116) = 38.0$ ,  $p < 0.0001$  (see Table 2).



***Baseline Characteristics Associated with Participation.*** In order to determine the effects of demographic (age, annual household income, years of education) and medical characteristics (time since diagnosis, clinical stage, treatment status, tumor size, and number of involved lymph nodes) on subsequent participation in the online support group, simple correlations with participation variables were obtained. Age, income, clinical stage, time since diagnosis, treatment status, and positive nodes were unrelated to any of the participation variables and were excluded from further analysis. Because tumor size and education were each independently associated participation, these characteristics were regressed as a block onto each of the participation variables (time spent on the web site, use of the coping exercises, length of posted messages, and percentage of words related to cognitive processing, emotion, and cancer).

Use of the coping exercises was significantly predicted by tumor size,  $F(1, 53)=5.17$ ,  $p=0.02$ , with smaller tumor size predicting greater use of the exercises. Tumor size also predicted more time spent interacting with the web site as a whole,  $F(1,53)=5.98$ ,  $p=0.018$ . Education did not significantly predict use of the coping exercises or time spent on the web site. More years of education was associated with trends for increased length of messages sent to the group,  $F(1,45)=3.76$ ,  $p=0.059$ , and a higher percentage of words related to emotion,  $F(1,45)=3.72$ ,  $p=0.06$ . None of the demographic or medical characteristics were significantly associated with use of cognitive or cancer-related words.

We further sought to examine the relationship between baseline attitudes about cancer (self-efficacy for coping with cancer, health-related locus of control, and coping styles) and subsequent participation in the group. Baseline attitudes were entered as a block in separate regression models predicting each of the participation variables. Greater use of the coping exercises was significantly associated with higher self-efficacy for affective regulation,

$F(1,44)=6.13$ ,  $p=0.017$ , lower overall self-efficacy for coping,  $F(1,44)=5.61$ ,  $p=0.022$ , and greater levels of approach coping,  $F(1,44)=7.80$ ,  $p=0.008$ . Total time spent interacting with the web site was associated only with greater approach coping,  $F(1,44)=5.60$ ,  $p=0.022$ . Longer message length was associated with lower self-efficacy for seeking support,  $F(1,39)=7.57$ ,  $p=0.009$ . Higher approach coping significantly predicted greater use of emotion words,  $F(1,39)=11.0$ ,  $p=0.002$ , and greater use of words related to cognitive-processing,  $F(1,39)=4.10$ ,  $p=0.05$ . Having a higher degree of external locus of control was associated with trends for use of fewer affect words,  $F(1,39)=3.65$ ,  $p=0.064$ , and use of fewer cognitive words,  $F(1,39)=3.81$ ,  $p=0.058$ . None of the baseline attitudes was associated with use of cancer-related words. Taken together, these models accounted for between 12% (for cancer-related words) and 34% (for emotional words) of the total variance in the participation variables.

***Baseline Characteristics Associated with Outcomes.***

*Quality of Life Outcomes.* Change in participants' perceived health status by the end of the 12-week study was significantly predicted by time since diagnosis,  $F(1,25)=4.09$ ,  $p=0.05$ . Shorter intervals between diagnosis and participation in the study were associated with greater improvements in health status. Improved overall quality of life scores were associated with shorter time since diagnosis,  $F(1,19)=8.19$ ,  $p=0.01$ , and greater annual household income,  $F(1,19)=4.23$ ,  $p=0.05$ . After adjusting for these baseline characteristics, none of the variables measuring attitudes toward illness were associated with changes in health status or overall quality of life.

*Physical Outcomes.* Changes in physical well-being were associated with treatment status,  $F(1,29)=13.00$ ,  $p=0.001$ . Participants who were in treatment at the start of the 12-week study showed greater improvements in physical well-being than patients not in active treatment. Upon adjusting for treatment status, improved physical well-being was also associated with higher

levels of external locus of control,  $F(1,29)=5.65$ ,  $p=0.024$ . Fewer experienced physical symptoms was predicted by a longer time since diagnosis,  $F(1,29)=10.0$ ,  $p=0.004$ . Again, after adjustment for time since diagnosis, higher levels of external locus of control predicted a reduction in the number of reported physical symptoms,  $F(1,29)=9.12$ ,  $p=0.005$ . Reduced impact of breast-cancer specific symptoms was not associated with any baseline demographic or medical variables but was associated with lower self-efficacy for maintaining activity and independence,  $F(1,26)=4.81$ ,  $p=0.04$ , greater self-efficacy for accepting cancer and maintaining a positive attitude,  $F(1,26)=10.3$ ,  $p=0.004$ , and higher levels of external locus of control,  $F(1,26)=16.8$ ,  $p=0.0004$ .

*Functional Outcomes.* Improved functional well-being was associated with higher annual household income,  $F(1,21)=9.61$ ,  $p=0.005$ . After covarying for the effect of income, greater functional well-being was also predicted by greater external locus of control,  $F(1,21)=8.54$ ,  $p=0.008$ .

*Emotional Outcomes.* Improved emotional well-being was significantly associated with having more nodes with metastatic breast cancer at baseline,  $F(1,26)=5.01$ ,  $p=0.03$ . After adjusting for this effect, lower levels of avoidance coping predicted improved emotional well-being,  $F(1,26)=4.36$ ,  $p=0.047$ . Improved levels of anxiety were associated with having more positive nodes,  $F(1,26)=5.55$ ,  $p=0.026$ . None of the attitudes toward illness predicted changes in anxiety level. Changes in symptoms of depression or total impact of events were not significantly predicted by any of the demographic, medical, or attitudinal factors.

*Social Outcomes.* Improved social and family well-being was associated with less time since diagnosis at entry into the study,  $F(1,24)=7.02$ ,  $p=0.014$ . Upon adjustment for time since diagnosis, self-efficacy for accepting cancer and maintaining a positive attitude was marginally

associated with improved social and family well-being,  $F(1,24)=4.06$ ,  $p=0.055$ . Greater perceived available social support was associated with younger age,  $F(1,33)=6.91$ ,  $p=0.013$ . Increased number of available social supports was associated with clinical stage,  $F(1,27)=6.82$ ,  $p=0.0006$ , such that women with clinical stage I breast cancer showed greater improvement than women with stage 0 or 2. After adjusting for clinical stage, lower levels of avoidance coping were associated with more individuals available to provide social support,  $F(1,27)=7.13$ ,  $p=0.013$ .

***Impact of Participation on Outcomes.*** LIWC participation variables (i.e., average word count of messages, percentage of words related to emotional processes, and percentage of words related to cognitive processing) were not predictive of changes in outcome. Because participants exhibited considerable variability across messages in message length and use of words related to emotion and cognitive-processing, we chose to analyze the relationships between total *numbers* of words used in each word category rather than *percentage of total words* within each message. This analytic strategy captured more variance in each of the primary outcome measures.

***Quality of Life Outcomes.*** Change in self-reported health status was not associated with any of the participation variables. However, increased overall quality of life scores were predicted by higher total length of messages posted to the online group,  $F(1,23)=7.95$ ,  $p=0.01$ , and lower total number of emotion words used over the course of the study,  $F(1,23)=4.30$ ,  $p=0.05$ . The set of participation variables accounted for 69.5% of the total variance in overall quality of life scores.

***Physical Outcomes.*** Change in physical well-being scores was associated with higher total message length,  $F(1,23)=6.19$ ,  $p=0.02$ , and lower use of words related to cognitive processes,  $F(1,23)=5.77$ ,  $p=0.02$ . Trends for fewer reported physical symptoms were associated with greater use of the coping exercises,  $F(1,23)=3.22$ ,  $p=0.09$ , and use of fewer words related to

emotion,  $F(1,23)=4.04$ ,  $p=0.056$ . The impact of breast cancer-specific symptoms was significantly reduced by greater use of the coping exercises,  $F(1,23)=5.59$ ,  $p=0.027$ . The set of participation variables accounted for 75.2% of the variance in breast-cancer specific symptoms, 68.2% of the variance in total reported symptoms, and 37.8% of the variance in physical well-being.

*Functional Outcomes.* Improved functional well-being was predicted by higher total length of messages posted to the group,  $F(1,23)=7.44$ ,  $p=0.01$ . The set of participation variables accounted for 57% of the variance associated with change in functional well-being.

*Emotional Outcomes.* Reduced total impact of events scores were predicted by greater use of words related to emotion over the course of the study,  $F(1,23)=4.61$ ,  $p=0.043$ . Changes in depression, anxiety, and overall emotional well-being were not associated with any of the participation variables. The participation variables accounted for 74.8% of the variance in impact of events, 48.3% of the variance in depression, 64.1% of the variance in anxiety, and 76.7% of the variance in emotional well-being.

*Social Outcomes.* Improved social and family well-being was predicted by lower use of emotion-related words during the study,  $F(1,23)=5.75$ ,  $p=0.025$ , and a trend for greater length of messages submitted to the group,  $F(1,23)=3.19$ ,  $p=0.088$ . Improved total perceived available social support was also associated with lower use of emotional words,  $F(1,23)=5.82$ ,  $p=0.024$ . The set of participation variables accounted for 68.2% of the variance in social well-being and 87.8% of the variance in perceived social support.

Finally, in order to evaluate the relative contribution of baseline characteristics and participation in the therapy group on changes across outcome measures, the effects of participation on outcome were tested after adjusting for demographic factors, medical

characteristics, and attitudes about illness that were previously shown to be significant predictors of outcome. After adjusting for these baseline characteristics, none of the participation variables were significantly associated with improvements in outcome.

## **Discussion**

Results of this study demonstrate that individual differences and degree of involvement in a psychosocial support intervention are associated with subsequent outcomes of the treatment. Demographic and medical characteristics of participants were associated with both participation in the treatment program and changes in outcome measures. Demographically, age and education were not generally associated with use of the web site or outcomes, although women with more education exhibited trends towards sending longer messages with more emotion-related words. Having a greater annual household income was predictive of improvements in functional well-being and overall quality of life. These findings suggest that among the increasing number of women with access to the Internet, women across a range of ages and educational backgrounds are likely to use online support groups in similar ways. The effect of income on health has been widely reported (Jakovljevi et al., 2001; Marmot, 2002). That women with greater household income were more likely to show improved quality of life and functional well-being may simply reflect better access to health services. Indeed, women in this study who had consulted a psychologist or psychiatrist after being diagnosed with breast cancer exhibited a higher annual household income than women who had not done so.

Medical characteristics of participants' breast cancer were also associated with participation and outcome. Women who reported their tumors to be less than 2cm at the largest dimension exhibited higher levels of interaction with the coping exercises and spent more time on the website. Because smaller tumors are generally associated with better survival outcomes

and less intensive treatment regimens, women with more favorable breast tumors at diagnosis may have had more time and energy to expend in a psychological support group than women with larger tumors at diagnosis. Consistent with this hypothesis, women with larger tumors in this study reported more physical symptoms and more frequent visits to their oncologist than did women with smaller tumors. Importantly, having more lymph nodes positive found to have invasive cancer was associated improvements in emotional well-being and reductions in anxiety over time. Additionally, entering the study closer to the time of diagnosis was associated with improvement in quality of life and social outcomes. These results suggest that adjuvant psychological therapies may be of particular benefit to women with greater levels of distress, either associated with poorer prognosis or with proximity to the initial diagnosis.

Attitudes about illness and coping styles were also significantly linked with participation in the treatment group and subsequent changes in outcome measures. Approach coping was associated with many of the measures of participation, including interaction with the web site, use of the coping exercises, greater use of emotion words, and greater use of cognitive-processing words. However, this coping style was not associated with changes in outcome measures. Avoidant coping style did predict greater levels of anxiety and lower emotional and social well-being at the end of the 12-week treatment group. The finding of a lack of association between approach coping and subsequent outcomes highlights the importance of providing interventions that appropriately channel active forms of coping into strategies that can effectively improve quality of life. Having an active approach to managing cancer-related lifestyle changes does not, in and of itself, predict improved well-being. Further, that avoidant coping was associated with declines in well-being suggests that tailored strategies to identify and redirect patients with this coping style may be of particular benefit. Having an external health-related

locus of control was associated with less emotional and cognitive involvement in the online therapy group but improved physical and functional well-being. These results are consistent with previous findings that, among patients with treatment-responsive cancers, external locus of control is associated with lower levels of distress (Andrykowski & Brady, 1994). Participants with strong beliefs that their health is influenced primarily by others, physicians, or chance may have perceived little reason to engage in high levels of affective or cognitive involvement in their written messages to the group.

General measures of participation in the online support group, use of the coping exercises and length of messages composed to the group were associated with improvements in outcome measures. Greater use of the coping exercises predicted a decline in the impact of breast cancer-specific symptoms and concerns, and longer messages to the group predicted higher quality of life and improved physical, functional, and social outcomes. However, word choice was not associated with clinical outcomes in the anticipated direction. Higher use of words related to emotion predicted greater emotional well-being but lower quality of life and reduced social well-being. Additionally, higher use of words related to cognitive processing predicted declines in physical well-being. Thus, our hypothesis that higher use of words related to affect and cognitive processing would be associated with improved outcomes was only partially supported.

The computer-facilitated Internet-based therapy program was not potent enough to result in improvements across the outcome measures assessed. Although participation in the group was associated with improvements in outcome measures, participation did not significantly predict improved outcomes after controlling for baseline characteristics. These results are consistent with previous findings that support-only groups do not improve outcomes (Jacobs et al., 1983; Telch & Telch, 1986; Gruber et al., 1993). Additionally, in comparing participant use of the



online support group with results reported in a recent qualitative study of the Breast Cancer Discussion List, an online, unfacilitated bulletin board for women with breast cancer, participants in the present study submitted messages with greater frequency and length than did participants in the unfacilitated bulletin board (Owen, Klapow, Roth, and Tucker, in review). Thus, the addition of structured coping exercises appears to increase participation in online support groups. Careful facilitation of groups by a health-care professional may be required to assist patients in the use of online coping exercises and to guide the content and direction of group interactions. Winzelberg and colleagues (2003) have recently reported that facilitated online support groups reduce depression and cancer-related distress associated with breast cancer. Facilitation may also prevent the study decline in participation that was observed in the present study.

In this sample of women with early-stage breast cancer, variables generated by LIWC did not predict changes across outcome measures. However, whereas average percentage of total words that were associated with emotion and cognitive processing did not predict changes in outcome, total number of words expressing affect and cognitive processing across the 12-week study was associated with changes in outcome. Thus, in evaluating psychological therapies that differ markedly from the expressive writing therapy for which LIWC was developed, LIWC requires additional validation. Compared with the word choice variables generated by LIWC, standardized measures of attitudes about illness and coping, as measured by baseline questionnaires, generally did a better job of predicting which patients would show benefits over time. More sophisticated textual analysis and behavioral observation systems are needed to identify communication and interaction patterns that predict improvements in outcome.

Limitations of the current study may limit the generalizability of the findings. Perhaps most importantly, the sample population exhibited very low levels of distress. Accordingly, for many of the women involved in the study, there was little room for improvement on the primary outcome measures. Future studies of internet-based adjuvant psychological therapies may benefit from having a sample size sufficient to analyze subgroups of participants with high levels of distress or closer to the initial diagnosis of cancer. The sample was also selected for women with access to the internet. As such, participants in the sample were not wholly reflective of the broader population of women with breast cancer treated at the UAB Comprehensive Cancer Center. Participants were slightly wealthier and more likely to be White. Additionally, the period of follow-up, limited to 12 weeks, may not have been sufficient to identify late-effects of the treatment program. Many of the participants elected to continue participation in their group, even at the end of the 12-week study. Fawzy and colleagues (1990) have demonstrated that the effects of psychosocial intervention for cancer patients may be more pronounced up to 6 months after the conclusion of the therapy program. Finally, the sample size obtained in the present study may not have been sufficient to detect changes across all outcome measures examined. Power calculations prior to initiating the study were based on a sample in somewhat greater distress, and changes in outcomes that were observed may have been too subtle for our practical recruitment effort to generate sufficient statistical power. However, the significant findings obtained were robust with respect to type II error.

The results from the present study bolster a growing body of literature that examines the process of therapeutic change within adjuvant psychological therapies for cancer. Through the identification of psychological mechanisms by which patients demonstrate clinically meaningful improvement, such therapies can be tailored to improve overall efficacy. Our current findings

suggest that computer-facilitated internet therapy can change online behavior, notably by encouraging coping-skills training, increasing the frequency of posting, and increasing the length of messages submitted to a support group. Facilitated groups may further enhance the therapeutic potential of online support by identifying coping patterns that are likely to be associated with poor outcomes and providing tailored feedback to alter these patterns. Additional work is needed to identify patterns of communication that are associated with therapeutic benefit. Extending the capabilities of LIWC and other text-analysis software programs to identify cancer-specific patterns of communication may be particularly helpful in this regard.

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### Author Note

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Table 1. Demographic characteristics of participants.

|                                      | Participants<br>(n=66) | s.d.   |
|--------------------------------------|------------------------|--------|
| Age (years)                          | 50.2                   | 9.6    |
| Median Annual Household Income (\$)  | 62,500                 | 77,081 |
| Education (years)                    | 15.4                   | 2.3    |
| Race (% White)                       | 91.4                   | --     |
| Marital Status (% Married)           | 85.7                   | --     |
| Time Since Diagnosis (Months)        | 26.2                   | 29.2   |
| Distance To Clinic (Miles)           | 100.6                  | 254.0  |
| Employment Status                    |                        |        |
| • Full-time (%)                      | 42.9                   | --     |
| • Part-time (%)                      | 14.3                   | --     |
| • Not Working Outside Home (%)       | 42.8                   | --     |
| Taking Prescription Medications for: |                        |        |
| • Depression (%)                     | 44.1                   | --     |
| • Anxiety (%)                        | 11.8                   | --     |
| • Pain (%)                           | 8.8                    | --     |

Table 2. Use of the web site across the 12-week study period.

|                                                   | Baseline – 4 weeks | 4 weeks – 8 weeks | 8 weeks – 12 weeks |
|---------------------------------------------------|--------------------|-------------------|--------------------|
| Mean Words per Message<br>(sd)                    | 337.4<br>(173.0)   | 316.9<br>(167.1)  | 285.4<br>(113.8)   |
| Mean % of Cognitive Words<br>(sd)                 | 6.2<br>(1.5)       | 7.1<br>(1.6)      | 7.0<br>(1.3)       |
| Mean % of Emotion Words<br>(sd)                   | 4.1<br>(1.5)       | 5.1<br>(1.3)      | 5.4<br>(1.3)       |
| Mean % of Cancer Words<br>(sd)                    | 0.13<br>(0.15)     | 0.06<br>(0.12)    | 0.08<br>(0.15)     |
| # of Log-Ins<br>(sd)                              | 14.1<br>(16.8)     | 9.0<br>(13.1)     | 9.2<br>(14.0)      |
| # of Hits to Coping Exercises<br>(sd)             | 35.2<br>(39.6)     | 25.6<br>(58.0)    | 8.7<br>(17.2)      |
| # of Hits to Bulletin Board<br>(sd)               | 23.5<br>(26.3)     | 11.7<br>(13.6)    | 15.1<br>(20.4)     |
| # of Messages Posted to<br>Bulletin Board<br>(sd) | 5.1<br>(5.3)       | 1.9<br>(2.7)      | 2.1<br>(3.2)       |